

TESTIMONY

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By

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Hearing on

Progress Since 9/11: Protecting Public Health and Safety of the Responders and Residents

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Thank you for having invited me to testify before you today. My name is Robin Herbert, MD. I am an Associate Professor in the Department of Community and Preventive Medicine of the Mount Sinai School of Medicine, and have served alongside Dr. Stephen Levin as Medical Co-Director of the Mount Sinai Center for Occupational and Environmental Medicine (COEM) since 1990 and also as Co-Director of the World Trade Center Worker and Volunteer Medical Screening Program and the World Trade Center Health Effects Treatment Program at Mount Sinai. I have recently been appointed Director of the World Trade Center Medical Monitoring Program Data and Coordination Center. My Curriculum Vitae is attached.

As we approach the fifth anniversary of the terrorist attacks of September 11, 2001, it is a fitting time to both remember those who perished in the horrific events of that day, and to take stock of how well we, as a nation, are caring for those responders who have subsequently fallen ill and those who may become ill in the future. These brave men and women unwittingly suffered massive environmental exposures after 9/11. Although it has not been confirmed, an estimated 40,000 people performed rescue, recovery, restoration of essential services, and clean up in the aftermath of the disaster. These responders included both traditional first responders such as law enforcement officers, EMS workers, and fire fighters, as well as a diverse population of civilian workers and volunteers, including operating engineers, laborers, ironworkers, telecommunications and other utility workers, transit workers and others. While responders came from a wide range of occupations and backgrounds, they worked shoulder to shoulder, united in their selflessness, in order to rescue victims, and quickly clean up and restore essential services to lower Manhattan. Now, as many have become ill, I hope they will all receive the medical and mental health care that they need and deserve, regardless of their occupation at Ground Zero, their health insurance status, or whether or not they find themselves reliant upon the New York State Workers' Compensation System as they attempt to receive critically necessary medical care.

Baseline Screening and Medical Monitoring Programs

Soon after September 11, 2001, various New York area health care providers, including those at the Mount Sinai COEM, began seeing workers and others with a range of health problems caused by their WTC exposures. This early work was supported by the ongoing grant from the New York State Department of Health that sustains our COEM and also by a special

grant from the Superfund Basic Research Program of the national Institute of Environmental Health Sciences (NIEHS) of the National Institutes of Health.

Thanks to advocacy efforts of our partners in organized labor and key legislators, notably Senator Clinton, Mount Sinai was awarded an \$11.8 million contract through NIOSH to design and coordinate a medical screening program for WTC workers and volunteers; no money was allocated to provide for long-term monitoring or for treatment. A consortium of five healthcare centers in the New York/ New Jersey metropolitan area was established with support from this grant to provide one free, comprehensive, and confidential medical screening exam to each WTC worker or volunteer who participated in the various rescue and recovery efforts both at Ground Zero and the Staten Island Landfill, including the removal of debris, the restoration of vital services, and the clean-up of surrounding buildings in the WTC area. Additionally, we worked with the Association of Occupational and Environmental Clinics (AOEC) to coordinate a program component for responders who live outside of the New York/ New Jersey area. Comprehensive standardized examinations of WTC responders began in July 2002, with the goal of identifying possible WTC-related physical or mental health consequences. From its inception to its end in July 2004, the WTC Worker and Volunteer Screening Program provided examinations to a total of almost 12,000 patients, including 11,125 seen in the New York/ New Jersey area, of which 8,824 were examined at Mount Sinai alone, and an additional 650 patients seen by 34 clinics in 24 states.

From the very start of the MSP, it was clear that long term monitoring and treatment would also be needed. In February of 2003, after eight months of advocacy efforts and with the help of labor and elected officials, in particular Senator Clinton and Congress Member Carolyn Maloney with the support of the entire New York delegation and other key legislators, an additional \$90 million in federal funding was secured to create the WTC Medical Monitoring Programs coordinated by both Mount Sinai and the FDNY. In March 2004, Mount Sinai received the first of this federal funding from NIOSH to serve as a Data and Coordination Center for the World Trade Center Medical Monitoring Program, as well as a Clinical Center providing follow-up examinations once every eighteen months for a period of five years to responders who had been seen initially in the screening program. This initiative continues to provide the opportunity of free initial medical screening examinations for responders as well. It should be noted that the

WTC responders served by our programs comprise a highly exposed population which will require medical monitoring and access to treatment for WTC-related health conditions for their entire lives. However, the Medical Monitoring Program is currently funded through only 2009.

The WTC Medical Monitoring Program began seeing WTC responders in July of 2004 and as of July 31, 2006, has provided over 4,887 initial (Visit 1) examinations and 6,112 follow-up (Visit 2) examinations in the New York/New Jersey regional consortium. In combination with the first medical screening initiative, this represents a total of more than 22,000 examinations (both baseline and follow-up) provided to over 16,000 responders since July 2002. Initially awards were made to provide examinations only in the New York/New Jersey area. Mount Sinai received the first federal funding to provide Visit 2 and any subsequent examinations nationwide on July 27, 2005, and has since provided over 130 examinations nationally. In June 2006, Mount Sinai received funding to coordinate the provision of examinations to a total of only 60 former federal employees. Since June 2006, 23 men and women have received exams and another eleven have been scheduled to receive exams. However, many more former federal employees have expressed interest in participating in the MMP than was initially expected, and it has become clear that a coordinated medical program will best serve the needs of the responders. Everyone should be assured of the same quality of care regardless of whether they currently live in the NY/ NJ metropolitan area. With the anticipated increased need for an expanded national program, proper planning and increased funding must be allocated.

It is important to note that a large number of responders are still coming to the program for an initial examination five years after the attacks. Indeed, within the past year, more than 2,000 eligible responders became sufficiently concerned about their health issues and are now seeking their first examination. This phenomenon highlights the need for continued funding for initial screening examinations, as well as follow-up medical monitoring exams and treatment, which I will address in a moment. It can also help guide both our ongoing response to the 9/11 attacks as well as our planning for future disasters.

Medical Findings

Among the very first responders we examined under the auspices of the MSP, we saw disturbingly high rates of respiratory symptoms and pulmonary function test abnormalities, as

well as persistent and severe psychological consequences. These were published two years ago in the Morbidity and Mortality Weekly Report (September 2004). Earlier this week, we released the findings of the WTC Medical Screening Program, which is the most comprehensive analysis completed to date, based on a diverse population of 9,442 WTC responders whom we examined between July 2002 and April 2004 and gave consent to have their data aggregated. We found that:

- Some 70% of responders experienced new or worsened respiratory symptoms while engaged in their efforts in or near Ground Zero. At the time of examination, 59% were still experiencing a new or worsened respiratory symptom;
- One third had abnormal breathing tests, which was a percentage far higher than we had expected; and that
- Among responders who had never smoked, we saw more than double the expected rate of breathing test abnormalities – 28% in our population versus only 13% in the general US population. This is a particularly striking finding because our patients tended to be very healthy workers before September 11 – they had to be extremely fit in order to work in trades such as construction and law enforcement. The most common abnormality we observed, a low forced vital capacity, was more than five times more prevalent in our population than would be expected.
- Early arrival to work on the rescue and recovery effort was significantly associated with an increase in the rates of respiratory symptoms and breathing test abnormalities. Indeed, the highest rate of abnormalities was observed among responders who were actually engulfed in the dust cloud. This finding is of particular concern because 70% of our patient population worked at Ground Zero between September 11 and 13, when exposures were most intense. The very strong relationship between time of exposure and the prevalence of symptoms and breathing test abnormalities strongly confirms the relationship between World Trade Center response work and respiratory disease.
- We also asked our patients if they had seen a doctor for a health problem in the six months prior to and the six months following September 11. We found sharp increases in incidence rates of certain illnesses:

- 40% of patients ever diagnosed with sinusitis were examined by a physician in the six months after September 11 compared to only 12% who sought medical attention in the 6 months prior
- 45% were diagnosed acute bronchitis in the six months following the disaster compared to only 12% diagnosed before and
- 10 times more responders were diagnosed with pneumonia in the six months after September 11 than in the six months before.

In short, the World Trade Center responder patients were highly exposed, they were highly symptomatic, and they had high rates of breathing tests abnormalities as long as 2 1/2 years after the disaster. These findings are consistent with the findings from other studies such as the FDNY studies led by Dr. David Prezant, and they underscore the magnitude of the problem of persistent respiratory illness among WTC responders.

Medical Treatment Programs

One of the greatest concerns among the responders is how and where they will be able to receive proper follow up diagnostic testing and treatment for WTC-related physical and mental health conditions. As we watched so many responders fall ill, and in many cases chronically so, it has been apparent since early on that medical screening and monitoring alone was insufficient - long-term medical treatment would be equally necessary. This problem was compounded by the fact that 38% of patients seen in the last year in our Treatment Program either had no health insurance to begin with or lost their insurance after they fell ill as a consequence of their work following 9/11. At Mount Sinai, we at first welcomed responders, as well as affected area residents and office and other area workers into our state funded Mount Sinai Center for Occupational & Environmental Medicine.

However, we were overwhelmed by the demand for treatment resources and, because no federal funding was provided for treatment, we soon sought and received funding from private philanthropic sources to establish the World Trade Center Health Effects Treatment Program, a program designed to provide diagnostic testing and treatment as well as assistance in obtaining needed benefits, for responders with WTC-related physical health problems. Given recent news reports, I should reiterate that this program is and has always been open to all eligible WTC

responders in need of treatment, including immigrant workers and without respect to insurance status with no out-of-pocket cost to responders. Similar programs were funded to meet the mental health needs of responders. To date, the physicians at the Health Effects Treatment Program at Mount Sinai have had over 8,000 medical visits with 2,137 patients, and the social work staff has had 6,167 visits with 1,934 clients, with significant overlap between the medical and social work patient populations.

Among 1,443 patients seen in the past year, from August 2005 through July 2006 in the World Trade Center Health Effects Treatment Program:

- Fully 84% are still suffering from some kind of upper respiratory illness, such as chronic sinusitis.
- 47% have persistent lower respiratory problems such as asthma and WTC cough.
- 64% have some kind of gastrointestinal illness, mostly gastroesophageal reflux disease.
- 37% have persistent mental health consequences related to the World Trade Center disaster, including depression and post-traumatic stress disorder.
- 31% have chronic musculoskeletal problems, often from injuries that occurred when working on the pile.
- Additionally, a large number of patients suffer from multiple WTC-related conditions, rendering diagnosis and treatment particularly challenging.

While it is not unusual to see a high level of physical and mental illness in a clinical patient population, what is quite striking is persistence of these illnesses four and a half years subsequent to exposure at the WTC site. It is absolutely essential that these men and women receive the best of care from healthcare professionals who are familiar with the health impact of the World Trade Center disaster – a large number of people have been misdiagnosed and/or received inappropriate treatment for their conditions. We are currently working to develop a coordinated treatment program which is fully integrated into each of the Medical Monitoring Program Clinical Centers which will help to ensure that responders are able to receive standardized care from physicians who have experience treating WTC-related conditions. I would also like to take a moment to note that, while our focus has been on the workers and volunteers who responded to the disaster, these health effects are not limited to this population –

there are thousands upon thousands of people who sustained similar exposures and who are not eligible for any federally-funded medical monitoring or treatment program.

Moreover, the impact of the World Trade Center disaster is not limited merely to health consequences. Many of our patients are so disabled by chronic pulmonary problems that they are no longer able to work. These patients often lose their jobs, their health insurance, and find that Workers' Compensation insurers are fighting their claims. For these reasons and more, a social work component has been critical to our service provision. Our social work team is dedicated to helping these responders access benefits programs, file for Workers' Compensation, and otherwise resume living as normal a life as possible. However, the resources we are presently capable of offering are simply too limited.

Currently, generous funding from the American Red Cross has enabled Mount Sinai, FDNY, and the other Clinical Centers to expand WTC related treatment programs in order to better serve responders. The AOEC has also received funding to provide treatment to those who live outside the New York/ New Jersey metropolitan area. While we are very grateful to these philanthropies for stepping in to fill such important patient needs, we have always considered private funding to be a stopgap rather than a long term solution to what is certain to be a long term problem.

Thanks in large part to the diligent work of our partners in organized labor and legislators, including Congress Members Maloney and Fossella, Senator Clinton and the NY delegation's support, Congress returned \$125 million initially earmarked to meet responder health needs in December 2005, with \$75 million allocated to provide continuing medical treatment and monitoring for responders. The program providers at Mount Sinai and our consortium partners anticipate using the almost \$27 million that has been set aside for our consortium to provide treatment for physical and mental health illnesses, including medications and in-patient care. Tens of thousands of responders who are presently ill or will become ill as a result of their service to our nation will benefit from this additional funding. The patient population to benefit from this includes the thousands of responders who are presently ill and those who may still become ill as a result of their service to the nation. However, \$27 million could easily be spent in as little as one year if this money is used to provide all non-FDNY

responders with medications and both in-patient and out-patient treatment for any WTC-related medical and psychological conditions at multiple regional sites as well as nationally. Due to the horrific and unprecedented nature of the exposures at Ground Zero and the Staten Island Landfill, we can only begin to guess at what the future holds for these responders and know that the current funding remains grossly inadequate. Because of the complexity of establishing a program of this nature, it is anticipated that proposals to receive federal funding will be solicited, with awards and release of funding expected in about March 2007.

We are indebted to these workers for their selfless actions, and we are obligated to provide them with the absolute best of care. We, as healthcare providers, should not be forced to ration care, just as those who are the most gravely ill should not be forced to choose between food and medicine. Consistent, adequate federal funding should be provided to take care of those who responded to the attack on our nation.

Lessons Learned and Current and Future Needs and Gaps

Lesson #1: The Need to Establish New Medical Resources.

Although New York had an extensive hospital network and a strong public health system on September 10, 2001, this preexisting infrastructure was in no way sufficient to provide unified and appropriate occupational health screening and treatment in the aftermath of 9/11. Disaster sites are invariably scenes in which exposures are intense and uncontrolled, and in which illnesses are severe and unpredicted. The rapid establishment of highly competent medical resources is necessary to cope with such situations. This need became apparent soon after September 11th, as occupational medical centers as well as other varied health care providers began seeing workers and others with a range of upper airway, lung, gastrointestinal, and mental health symptoms and reports of these occurrences began to appear.

An invaluable component of the MMP is its ability to identify patterns of WTC-related health conditions, both physical and psychological. However, additional funding is needed to allow for continuing data tracking and analysis of exams and treatment so that we can better tailor subsequent monitoring examinations and provide appropriate treatment. We recognize the potential of increased cancer rates and the enormous impact that cancer would have on the WTC

responders and their families and we have said from the beginning that we are concerned about the possibility of cancers in responders, and especially about cancers that may be triggered by asbestos and other toxic chemicals. We are working with all the Clinical Centers to develop an active surveillance system to allow participants to inform us of any changes in their health status, such as the development of cancer, during the time period between their visits. This surveillance system will be linked to cancer registries and death registries, so that we can collect as much information as possible about our patients, and their health status.

The mandate of these programs included the referral of responders for follow-up diagnostic studies and appropriate treatment when warranted by the clinical findings of their examinations, yet no resources were initially allocated to enable us to provide such care. This was a clear shortcoming that must be addressed in the aftermath of future disasters, whether natural or man-made. Many of the responders had no health insurance and those who did found it difficult to obtain treatment guided by the expertise needed in the evaluation and management of their illnesses.

Lesson #2: The Inadequacy of Workers' Compensation Programs in the Context of Disaster

Many of the WTC responders who are our patients filed claims with the Workers' Compensation system to obtain coverage for their medical care only to find their cases opposed by Workers' Compensation insurers or by self-insured employers. The result was that many hundreds of brave workers who had volunteered to serve this nation at the site of the World Trade Center had to endure many months of needless and physically damaging delay in receiving medical care. We do not subject members of our armed services to such delay, and it is unconscionable that our health care system imposed these burdens on WTC responders. Indeed, many responders found themselves unable to work in their usual trades where irritant exposures, readily tolerated before September 11th, now provoked asthmatic symptoms. This resulted in a loss of their health care benefits when they were needed most.

To address this situation, in August of this year, Governor Pataki signed into law new legislation that removed one of the barriers that these responders have had to overcome in the New York State Workers' Compensation system. But, five years after the disaster, many responders are still in need of follow-up treatment for WTC-related physical or mental health

illnesses.

Lesson #3: The Persistence of Illness

Based on our accumulated knowledge in the aftermath of 9/11 and general medical science, there is no question that, as a result of their horrific exposures, thousands of World Trade Center responders have developed chronic and disabling illnesses that will likely be permanent. Sadder still, we continue each year to see new patients in the Medical Monitoring Program who have either never been treated for their WTC illnesses, or who have received delayed or sub-optimal treatment. Some of these delays are due to the aforementioned shortcomings of the Workers' Compensation system. We also now know – based on over four years of follow-up since the attacks – that it is likely that thousands of World Trade Center responders will need long-term medical care for their World Trade Center related physical and mental health conditions.

Lesson #4: The Need for Continuing Medical Surveillance

Continuing medical surveillance and follow-up will be essential for the WTC responder population. Responders were exposed to many carcinogens at the WTC site, including asbestos, benzene, and dioxins. For many patients in our program, the fears of future diseases like cancer, which can take as long as twenty to thirty years to develop, loom as large or larger than concerns about their acute ailments. Indeed, because WTC responders sustained unprecedented exposures for which the long-term consequences are unknown, we strongly recommend screening this population for at least twenty to thirty years in order to ensure that diseases that can develop years after exposure can be detected when they are still treatable.

Lesson #5: The Need for Uninterrupted, Guaranteed Long-Term Federal Funding

As I mentioned before, current funding will permit the WTC Medical Monitoring Program to conduct screening examinations of 12,000 WTC responders once every 18 months for a total of five years only. Philanthropic sources have provided funding for the Health Effects Treatment Program, but this is limited in scope and duration. It is urgent that funding be made available to provide access to medical and mental health care for all who sustained health consequences from the World Trade Center disaster. This can be achieved by:

- Supplementing the current appropriations to provide medical monitoring and treatment for the lifetime of responders through a coordinated consortium of clinical centers with expertise in screening for, diagnosing, and treating WTC-related health conditions.
- Guaranteeing access to the diagnostic testing necessary to confirm or rule out possible WTC- related health problems identified in the screening examinations and providing treatment for all WTC related health problems identified;
- Integrating monitoring and treatment programs to ensure that those who develop future health problems related to the WTC exposures are able to receive treatment for those conditions including both out-patient and in-patient care as well as medications;
- Supporting clinical research to better understand and track the human health consequences of World Trade Center exposures and identify treatment modalities for those conditions;
- Providing adequate resources for the local residents, office and other area workers and school children whose proximity to the site may have caused them to suffer similar exposures as the responders. Workers and volunteers involved in rescue recovery efforts, workers, residents, and school children from areas affected by WTC contamination have thus been left at the mercy of a patchwork of health care resources, posing a difficult challenge for the screening programs to carry out their referral responsibilities.

Lesson #6: The Need to Remember the Lessons Learned and to Apply them in Future Disasters

It is clear in the aftermath of the WTC disaster, and has been reemphasized by the events in New Orleans after Hurricane Katrina, that there is an urgent need for our nation to improve its disaster response planning and also to ensure adequate funding for these programs. We learned from the Vietnam War and the first Gulf War how important mental health problems are in the wake of extreme stress and we applied those lessons in the Balkans and after September 11th to

good effect. Now we need to learn from the terrible events that transpired in New York City how to rapidly fund and establish medical screening and treatment programs. Disease and injury are the inevitable consequences of disaster, and we need to plan for them. We need to study these events to learn how to best conduct rescue and recovery operations that will not only minimize the loss of life among disaster victims, but also curtail disability and illness among the responders. We need to commit ourselves to sustain these programs over the long term to keep faith with those responders who rise in the hour of need to serve America.

Conclusion

Five years following the attacks on the World Trade Center, thousands of the brave men and women who worked on the rescue, recovery, and clean up efforts are still suffering. Respiratory illness, psychological distress, and financial devastation have become a new way of life for many of the responders. I hope that my comments today will serve as a reminder of the long-term and widespread impacts of this disaster.

Thank you. I shall be pleased to respond to your questions.